A PATIENT'S JOURNEY

# Sleep apnoea: from person to patient, and back again

Peter C Gøtzsche,[1] Søren Berg[2]

[1]Copenhagen, Denmark
[2]ScanSleep, Nørre Farimagsgade 13, 1 tv, DK-1364 Copenhagen, Denmark
Correspondence to: P C Gøtzsche
pcg@cochrane.dk

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The frustrations of the treatment offered for sleep apnoea made "being a patient" difficult

There was no doubt about the diagnosis. My sudden loud snoring bouts woke up not only my wife but also me. The bouts were dramatic, like a deep sea diver gasping desperately for air after a world record attempt, or the roar of a ferocious animal just before the killing attack. Despite having spent eight hours in bed, I was sometimes exhausted and sweated during the day. Occasionally, I had irresistible urges to sleep at inconvenient times—when driving or during a dinner with guests, for example. The urge could be so pronounced that it felt very "painful," in which cases I had to leave the party to get a nap, with the excuse that I didn't feel well. This was certainly true, and it sounded better than to say I was tired.

I finally gave in to the symptoms and visited an ear, nose, and throat specialist, who handed out some equipment to monitor the sleeping pattern. As expected, the electronic recordings showed apnoea periods, which lasted up to a minute. The surgeon first suggested removing the uvula and possibly other tissues. This made me think of Mark Twain, who remarked that to a man with a hammer everything looks like a nail. I declared that under no circumstances would I accept surgery, which was not only irreversible but could also be harmful. Furthermore, I told him that there were no data from randomised trials that showed such surgery worked.[1 2] The surgeon then suggested using continuous positive airway pressure (CPAP), which I accepted, not knowing that its benefits in mild to moderate sleep apnoea are inconclusive.[2] He referred me to a sleep centre, and I asked him to send a copy of his file with the recordings to the centre so that they would be available when I arrived.

The first thing the sleep specialist wanted to do was to make sleep recordings. It did not seem to matter that another specialist had already done them. I protested and told him that new recordings were unnecessary, as the diagnosis was indisputable. It then turned out that he had not received the recordings, but I insisted he should request them, rather than subjecting me to a superfluous test.

The missing recordings were not really a problem for the specialist, however. He unpacked a CPAP set and explained carefully how to use it. He mentioned that I could get a special permit allowing me to carry the apparatus as hand luggage when I was flying. I explained that I did not intend to carry it with me when travelling, as I did not feel that sick. I had sometimes cared for patients at an intensive care unit who were equipped with similar apparatuses, and I did not want to look like a desperately ill patient.

The specialist explained that, to allow people to fall asleep, it took 20 minutes before the apparatus started working after it was turned on. He also said that if the inhalation pressure was too high I could adjust it, but he did not tell me how.

Back home, I unpacked the CPAP apparatus with great suspicion, feeling badly about my new role as an intensive care patient. I usually fall asleep within a minute or two, but now I was wide awake, counting the minutes till the apparatus started working. When it started, it blew me up like a balloon. It was very unpleasant and after a while my throat dried out. I consulted the instruction manual, which was about a hundred pages, but could not find any description of one of the most essential functions, how to reduce the pressure. I gave up, dismantled the machine, and slept immediately. My wife convinced me to give it another try the next evening, but the same sequence of events unfolded.

On the third day, I decided to read the instruction manual more carefully and found a page, which, considering its dire text, curiously was not located at the beginning of the manual. It said that under no circumstances should one use the apparatus before having read that particular page. Reading on, I discovered that there was no guarantee that the apparatus would not kill me. I figured out that if it malfunctioned, I would reuse my own breath and die peacefully without triggering any alarm bells and without any intensive care nurses rushing to my rescue. Startled by this, I searched PubMed and the internet but found no data on the risk of this lethal complication.

I decided that the inconvenience of my condition did not justify any risk of dying because of the treatment. I had consulted the medical literature before I saw the surgeon and knew that observational studies indicated that sleep apnoea increases the risk of cardiac disease. But so many things in life increase that risk, and observational studies can be misleading. Prolonged oxygen deficiency may not be good for the heart, but I have no risk factors for heart disease and do a lot of sports. Thus these observations didn't count in my private decision analysis.

At the next visit to the sleep centre, the specialist asked me how it went. I told him about my experience and

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**Previous patient journeys**
- Two hip replacements (*BMJ* 2010;340: c1052)
- Living with lymphangioleiomyomatosis (*BMJ* 2010;340: c848)
- Recovering from severe brain injury (*BMJ* 2010;340: c839)
- Dopa responsive dystonia (*BMJ* 2010;340: c668)
- Cardiomyopathy (*BMJ* 2009;339: b4210)

### A DOCTOR'S PERSPECTIVE

Obstructive sleep apnoea is characterised by recurrent partial or complete obstructions (hypopnoea or apnoea) of the upper airways during sleep. If excessive daytime sleepiness or unrefreshing sleep and impaired daytime function is present, along with an overnight monitoring showing five or more obstructive events per hour, the criteria for obstructive sleep apnoea syndrome are fulfilled.

Symptoms of obstructive sleep apnoea almost always include snoring, but the intensity varies and is not correlated with the severity of sleep apnoea. Other important symptoms are nocturnal diuresis, gastroesophageal reflux, frequent awakenings, and restless sleep. Typical daytime symptoms are morning drowsiness, headache, and varying degrees of daytime sleepiness, concentration difficulties, and depression.

The number of sleep related obstructive breathing events per hour determines a severity index, the apnoea-hypopnoea index (AHI), where 5-15 is mild, 15-30 is moderate, and over 30 is severe. Obstructive sleep apnoea syndrome is defined as AHI >5, and excessive daytime sleepiness is normally approximated to 4% in men and 2% in women. However, obstructive sleep apnoea has been reported as occurring in up to 24% of men and 9% of women.[5]

Obstructive sleep apnoea covaries with cardiovascular disease due to the stressful effects of varying blood pressure, cerebral pressure, and repetitive hypoxaemia. The accompanying daytime sleepiness is a well known risk factor for traffic accidents.

For diagnosis of sleep apnoea, overnight polysomnography is the reference standard, but because of the high prevalence of the disorder, portable systems for home recordings have been developed. These should include measurement of airflow, respiratory effort, and pulse oxymetry. The portable systems differ in quality and do not include sleep electroencephalography, which is why time spent asleep has to be estimated. The sensitivity and specificity of the AHI therefore vary.

Generally accepted treatment modalities include mechanical interventions (continuous positive airway pressure (CPAP) or oral appliances (mandibular advancement devices, for example)), surgical procedures, and "conservative" measures (weight reduction, lifestyle modifications). It is widely accepted that patients with severe sleep apnoea (AHI >30) should be offered CPAP as first line treatment, whereas patients with less pronounced sleep apnoea may benefit from an oral appliance and in some cases a surgical procedure.

As in any other medical condition, decisions on and choice of treatment for obstructive sleep apnoea require a correct diagnosis, balancing subjective symptoms and objective findings, and cooperation of the patient. This depends greatly on the amount of relevant information accessible to the doctor and the patient's understanding of his or her medical condition and treatment options.

When deciding on CPAP treatment it is mandatory to give the patient detailed and correct information about the equipment and to choose the correct face mask. Follow-up after one week greatly improves patient compliance, as many start-up questions and misunderstandings may then be resolved.

This "patient's journey" illustrates a case in which dramatic subjective symptoms apparently contrasted with the objective recordings. This is not unusual, and it underlines the importance of having and communicating correct information when evaluating, diagnosing, and treating medical disorders.

Søren Berg berg@scansleep.eu

deliberations and returned the equipment. To my surprise, he told me that since my sleep apnoea was mild, he would not have recommended the apparatus in the first place. He had now received the recordings from the surgeon, and again to my surprise, he seemed to base his judgments on "laboratory values" rather than on the patient's symptoms. He also said that CPAP was considered to work only at certain ages and was not recommended after age 70. I replied that, approaching 60, I saw no reason to use this terrible, "patientising" apparatus, which might even kill me, in this little time window.

I told my story to two colleagues and one of them remarked that most patients cannot tolerate using CPAP for sleep apnoea. He sent me a paper that had found that only two of 35 patients used CPAP for seven hours for at least 70% of the nights.[3] It would have been nice to know this beforehand, as I would then not have felt so awkward when I tried to use what I felt was like firing at sparrows with a cannon, as my problems were not life threatening. If I had also known about the *BMJ* review that questioned the effect of CPAP in mild to moderate sleep apnoea I would not have consulted a doctor in the first place.[2]

My short guest visit as a patient was alarming. Worst of all, I had lost my autonomy when having appointments with doctors who told me what to do, and became a patient who other people might pity. I do not want any of that. I dropped the patient role, as I am not patient enough to consult doctors unless I am really ill.

A case always has three sides: yours, mine, and the correct one. My two doctors were pleasant and skilled colleagues. If this account has been unfair to them in any way, or inaccurate, I apologise. But what I have described is what I felt. And I believe we can learn a lot from patients' narratives.[4] What strikes me most from my own "patient visit" is that it is grossly unfair that a doctor like me, who does research and is used to searching for the best available evidence, is privileged in comparison to the vast majority of patients who cannot do this and therefore hope—and usually also think—that the doctor knows best. That is not always the case.

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SAFETY ALERTS

# Early detection of complications after gastrostomy: summary of a safety report from the National Patient Safety Agency

Frances Healey,[1] David S Sanders,[2] Tara Lamont,[1] John Scarpello,[1] Taofikat Agbabiaka[1]

See CLINICAL REVIEW, p 1074

[1]National Reporting and Learning Service, National Patient Safety Agency, London W1T 5HD
[2]Department of Gastroenterology, Royal Hallamshire Hospital and the University of Sheffield, Sheffield
Correspondence to: F Healey
frances.healey@npsa.nhs.uk

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This is one of a series of *BMJ* summaries of recommendations to improve patients' safety, based on reports of safety concerns, incident analysis, and other evidence. The articles highlight the risks of incidents that have the potential for serious harm and are not well known, and for which clear preventive actions are available.
To report adverse events to the National Patient Safety Agency, go to www.nrls.npsa.nhs.uk/

## Why read this summary?

Gastrostomies are used as a medium to long term feeding strategy for children and adults with additional dietary needs or an inability to swallow, and they may be inserted surgically, endoscopically, or under radiological guidance. About 15 000 gastrostomies are inserted annually in the United Kingdom.[1] Complications include chemical peritonitis, infection, bowel perforation, haemorrhage, and aspiration pneumonia. But early recognition and prompt action reduces the risk of serious harm or death.[2] Over six years (October 2003 to January 2010) the National Patient Safety Agency (NPSA) received 22 reports (including five incidents in children) from clinical staff of harm from delayed response to serious complications after gastrostomy insertion. Eleven patients died and 11 became critically ill. Reported complications included nine cases of leakage of feed into the peritoneal cavity and/or peritonitis, three colonic punctures, and two complications related to haemorrhage; underreporting is likely.[3]

Incidents were reported from settings that included general medical, surgical, and elderly care wards after gastrostomy insertion in an endoscopy or radiology unit; patients whose gastrostomy had been inserted in a day case unit sometimes returned to the unit or presented at emergency departments. A typical incident report reads: "Gastrostomy undertaken as planned within the Endoscopy Unit on [Friday]. Limited post-procedure vital sign recordings were undertaken on [Friday to Sunday], the patient was escalated to the on-call SHO on [Sunday] at 23:00 hours due to a raised CRP [C reactive protein] . . . the most likely cause was considered to be dehydration . . . on [Monday] the patient was noted to be less responsive . . . on-call SHO was of the opinion that this was due to the patients controlled drugs. She was seen on the [Tuesday] by the specialist who requested radiological investigations to rule out any perforation. The CT abdomen confirmed perforation . . . "

This summary is based on a safety report (known as a "rapid response report" or "RRR") on early detection of complications after gastrostomy, with key actions for staff, issued by the NPSA in March 2010.[1]

## What can we do?

For clinical staff caring for patients in the first three days after gastrostomy insertion (including those staff working in hospital wards, care homes, or the community (general practitioners and those working for out of hours services)), the NPSA recommends the following actions.

- In the immediate recovery period, ensure regular observations of temperature, blood pressure, pulse respirations, and pain score (to detect general complications such as haemorrhage, aspiration pneumonia, or sepsis).
- Ensure review by a senior member of staff before discharge.
- Be aware of "red flag" symptoms specific to gastrostomy, including pain on feeding, prolonged or severe pain after the gastrostomy, or external leakage of gastric contents (which could indicate internal leakage into peritoneum; incident data suggested such leakage was often treated instead as a minor skin care problem).
- If pain occurs on feeding, stop feeding immediately. Obtain advice from a senior colleague and consider computed tomography, a contrast study, or surgical review (as the incident review showed that staff did not consider the possibility of internal leakage of gastric contents but responded instead with pain relief or change of feeding speed).
- Tell patients and their carers about signs of complications and give them a contact number for urgent advice (data suggested carers did not know whom to call). The NPSA alert provides warning labels for local use.

The RRR does not give detailed advice on investigating and managing complications as this will vary with patients' circumstances and local service provision, and between adults and children.

## What else do we need to know?

The fatal and serious outcomes of the cases highlighted in the RRR reinforce the need for careful consideration when making decisions to feed a patient via a gastrostomy, also the subject of recent guidance from the Royal College of Physicians.[4] The benefits of gastrostomy feeding in patients with dementia are also contentious.[5] Careful counselling and a multidisciplinary approach are essential; patients (if cognisant) and carers should be given enough information to make an informed decision.

## How will we know when practice has become safer?

The NPSA will monitor reports it receives, especially for any that describe earlier recognition of complications and action taken to treat their causes. NHS organisations will also report on their compliance with the actions required by the RRR through the Department of Health's

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**Previous safety alerts**
- Reducing risks of tourniquets left on after finger and toe surgery (*BMJ* 2010;340:c1981)
- Improving the safety of oxygen therapy in hospitals (*BMJ* 2010;340:c187)
- Insertion of chest drains (*BMJ* 2009;339: b4923)
- Avoiding midazolam overdose (*BMJ* 2009;339:b4459)
- Combining stories with statistics to minimise harm (*BMJ* 2009;339:b4489)

Central Alerting System. National organisations with an interest in gastrostomy insertion may consider future audits of the prevalence of complications and overall mortality incurred by gastrostomy insertion, building on previous national mortality audits.[2]

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# The telephone rings...

The telephone call begins innocuously enough: "Hello, can I speak to Mr Smith please?" Now Mr Smith may or may not be there, but generally the reply is "Who's calling?"

This is usually followed by an awkward silence as I am still new to this game. I then say something like, "I'm sorry, but I need to speak to Mr Smith directly."

I wait for the response, and then it begins. They want to know who I am and why I want to speak to their husband/wife/daughter/son. As a family member, they feel that they have a right to know. I try to deflect their questions in the nicest possible way without breaching confidentiality. I know how it must sound, though, and eventually they are irritated. This is especially true when I, as a female doctor, have tried to contact a male patient and find myself speaking to his wife.

I reiterate that it is a local call, but that I need to speak to Mr Smith himself. Sometimes, grudgingly, they put me through. Others understandably are angry and bang down the telephone. I know what must ensue in the seconds after they hang up: they will try to trace the call but only receive an automated message that my number is withheld. This, together with my unwillingness to divulge my identity, makes it much worse when I phone the second time and Mr Smith is still not there. The person at the other end of the line is often quite angry by now.

If the matter is not urgent, I usually take the coward's way out at that point and write a letter. I dislike the daily battle over the phone. Even if my identity is hidden, I dislike arguing with people. As a specialist trainee working in primary care, I had not anticipated the complexities of contacting patients by telephone while maintaining confidentiality. It's certainly not something I had to do much of during my hospital jobs, as my relationship with patients usually ended when they left the ward.

I've asked the receptionists how they deal with these phone calls, as all too often they are the ones phoning about a warfarin dose or asking a patient to have a repeat blood test. Understandably, it is the part of the job they like the least. All for the sake of confidentiality. I stand by the reasons why this is important; it's just sometimes it seems ridiculous to have an argument with someone for the sake of a blood test they no doubt know their husband has had.

On the other hand, I have had patients relieved that we have not disclosed details, however minor, to family members. Many people, for one reason or another, do not want their family to know they have been to see the doctor. So, I'm glad the subterfuge serves its purpose; upholding confidentiality is central to the doctor-patient relationship. It's just that I wonder about the suspicions that are aroused in the minds of husbands and wives, and I dread the nameless, faceless battles in the days ahead.

**Vasandhara Mahendrayogam** GP specialist trainee year 1, Colchester Specialist Training Programme, Colchester
vasmahendra@hotmail.com

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